



SPECIAL NEWS FOR SPECIAL NEEDS



Issue 6

Winter, 2004



WINTER GREETINGS



How exciting - this is our second annual Winter Issue! It is so hard to believe that we are already in our second year of publishing our newsletter. We hope you have enjoyed it as much as we have enjoyed putting it together. We know how difficult it can be to attend evening support meetings or to find the time to research information on various topics. It is our hope that this newsletter will help to bring you support from other families along with valuable information and resources. We welcome your input at any time. This is a newsletter for our families and we really want you to be a part of it. Please call Sandy or Kellie to share your stories or to request we do research on a certain topic for an upcoming issue. In this issue, we have two wonderful parent stories along with an opportunity for you to become a Parent-to-Parent Volunteer and/or an advocate for your child. If you have any questions or would like additional information, please call us at any time. We hope you have a safe and warm winter season.

Kellie & Sandy

Family Support Specialists

Kellie 302-995-8617 kellie.mckeefer@state.de.us

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MAILING LIST



Please help us keep our mailing list updated. If you are currently receiving mailings from us and would like to discontinue them, please call Kellie at (302) 995-8617 or Sandy at (302) 422-1335 or (800) 752-9393. If you would like to receive our mailings (especially the newsletter) via e-mail, please call Kellie or Sandy with your e-mail address.



PLEASE JOIN OUR PARENT-TO-PARENT VOLUNTEERS

We've had several responses to our request for Parent-to-Parent Volunteers, but we would love to have more. If you would like to meet families of children with special needs facing challenges similar to yours, or if you'd like to help provide support to a family in need, please consider joining our group of Parent-to-Parent Volunteers. We will be meeting soon so that we can all get to know each other. This is a great opportunity to meet new friends. If you are interested, please call Sandy Ward at 422-1335 or Kellie McKeefery at 995-8617. You can also express your interest by calling your family service coordinator.



Check Out These
New Websites



- www.kidsource.com
Kidsource provides parents with useful information on safety issues, product recalls and new products available to enhance infant development. It also provides beneficial health care articles about fevers, colds, pinkeye and other childhood sicknesses.
- www.childrensdisabilities.info
Children's Disabilities Information is an informational website empowering parents of children with special needs. It includes articles specific to disabilities and provides information and resources available to families.



Delaware Health and Social Services, Child Development Watch





HELP! I CAN'T TAKE HIM ANYWHERE!

"I can't take him anywhere." Many parents report that their young children's behavior in public is problematic. Difficulties at restaurants and most notably the grocery store are commonly reported. And, it is often not feasible for parents to just leave the children at home.

Often times, these environments are far from "kid friendly" and are over-stimulating for young children. There are many temptations at eye-level for young children. The environment is often filled with bright lights, loud noises, and a lot of temptation.

Here are some tips to try to make the experiences less difficult:

Keep your child's developmental level in mind when taking him/her to the grocery store. How long does it take you to get through the entire experience, from leaving the house to returning and unloading the groceries?

Starting small will help guarantee greater success. Right now, it may not be realistic to have your child go up and down every aisle of a large supermarket. Therefore, taking your child on the smaller grocery store runs may be a good starting point.

Being prepared before you go will also help avoid disasters. Be sure you are not interfering with nap or mealtime, as children are generally more fussy and irritable during these times of day.

Bring a few toys or snacks with you along the way.

Don't be so focused on the sales and coupons that you inadvertently don't pay attention to your child.

Make shopping a game. Sing songs, play "I spy."

Let the child make decisions about little things. For example, hold up two boxes of cereal and let him/her decide which one. Although the parent has made the choice by narrowing the product down to two items, the child will feel empowered and important by being able to make this decision.

Be clear with your expectations and the potential rewards. This will help avoid power struggles. If you clearly state that the child can pick out candy in the checkout line if he/she behaves, then you have established the reward. If, on the other hand, the child begs for candy or a toy, then power struggles may result. Some parents have found the little quarter machines filled with candy and toys to be very powerful. When walking into the grocery store, the parent may say, "If we get through the store with no whining or tantrums, you can have a quarter when we leave to use in any one of these machines." Then, at the end of each aisle, the parent can praise the child and remind him/her of the potential prize at the end.

Written By: Jennifer S. Walinsky, Ph.D., AI duPont Hospital for Children

PARENT TIPS

ENCOURAGING WORDS

Encouragement can help children feel good about themselves and their parents. But it can also be overdone. Helpful words show appreciation without sounding like empty praise or "things parents are supposed to say." Here are some tips on encouraging your child.

Notice specific good acts and comment on them.

- **Tell your child how much you love her and how wonderful she is.** But she also needs to receive encouragement about specific actions. Instead of saying, "What a good girl you are," try saying, "You put your book back on the shelf." She will see her own action as helpful.
- **Pay attention to the things that your child gets right.** For example, if he usually pushes to the front of the line but remembers to wait this time, you might say, "I'm glad you remembered to wait to go down the slide when you saw Jason get to the ladder first," along with a smile or a hug.
- **Use words to help your child become aware of her own approach to problems.** "I noticed Maria wanted to play a different game than you did, so you suggested playing her choice and then playing yours. You looked like you were having fun together."

Notice your child's effort and be honest in praising it.

- **Support your child's good intentions.** Rather than saying, "What a beautiful card. You're a great artist!" try saying, "Daddy will really like the get well card you made."
- **Be careful not to go overboard with praise.** Your child may begin to doubt your judgment if you constantly tell him that he's the fastest boy or the best artist, especially if he knows others who are faster or who draw better pictures.

Avoid compliments that insult your child or others.

- **Don't praise your child in a way that sounds like criticism.** Saying, "*You actually remembered to put your coat away for once*" is not encouraging. If something your child has done is worth complimenting, let the compliment stand on its own.
- **Avoid insulting others while encouraging a child.** Saying, "*You are a much better helper than your brother*" may cause competition and resentment.

"I love you." "I'm proud of you." "I'm so glad you're my child." Children and adults feel good when they hear these words.

Source: Illinois Early Learning Project, University of Illinois
These suggestions were adapted from: Brazelton, T. Berry, & Sparrow, Jo shua A. (2001). Touchpoints three to six: Your Child's emotional and behavioral development (pp. 222-224). Cambridge, MA: Perseus.
Work and Family Resource Center. (1996). Praising children [Online]. Available: <http://www.cpirc.org/tips/praise.htm#Praising%20Children>



PARENTS' CORNER



MY STRONG SON!

By: Lindsay Martin (11/17/03)

Hello parents,

Hi. I am the mother of a one-year-old premature baby. My son Mark, Jr. was born at 35 weeks. Although that's not that early, I never thought that my world would change, not only for me, but my son too. Mark was born and weighed 4 lbs. 11.2 oz. He was born by emergency c-section. When they pulled him out, he had respiratory distress but other than being little, nothing else. Mark was immediately taken to the NICU at the hospital where he spent only two weeks. When Mark was in the NICU for those two weeks, it was the hardest thing to do when I went to see my baby to know that I could touch, kiss and hold my baby but couldn't take him home.

When Mark was discharged we were so excited but things were going to change fast. When Mark, Jr. was four weeks old, he was diagnosed with reflux. He was always throwing up formula and he was always crying which was hard on my husband and me. They prescribed medicines and always had to increase the dose. The doctors said he would be okay but he wasn't. Mark, Jr. got worse. The doctors ignored me when I said "There's something wrong with him." Over the next several months of his life, he was always in lots of pain; it's very hard to know your baby is in pain and you can't help him.

Finally, the doctors saw Mark's pain and referred him to a GI doctor but couldn't get an appointment to see the doctor for another two months. During that time, I ended up taking Mark to the emergency room twice. They admitted him for four days and did all kinds of tests. There was one test that showed the cause of all of his trouble. The doctors did an endoscopy and discovered he had erosion in the lining of his stomach. They fixed it by changing his formula and medication. He was like a different child. Then he got sick again and they did another endoscopy and saw that his erosion had gotten better but only to discover Mark, Jr. had developed a hiatal hernia. The doctors said it was rare to see that in a baby but it should go away.

Mark has been diagnosed with failure to thrive and also a feeding problem. Mark has had a lot of illnesses and he requires a nebulizer to help him breath. Mark is a very strong, happy and normal boy except for what's going on inside of him. I've been told that he doesn't look sick but you don't have x-ray eyes; he has a lot going on for him. Mark has now gotten a new doctor who has given me hope. I only want my son to live a normal life and maybe he can with the help of people who believe in helping him live a normal life. This has been a hard thing but I don't regret a moment of it. I love my son and so do my husband and daughter.

Thanks for reading this, it means a lot!

Lindsay

CHECKLIST FOR TAKING CARE OF YOURSELF



- Write down all of the things your child has done in the last week that have made you laugh and smile.
- Make a list of the things you feel guilty about. Talk over that list with another person. Cross off the ones you are not responsible for. Cross off the ones you can't change. Make a plan of action for dealing with the rest.
- Look back at the storms you have weathered since your child was born. Congratulate yourself on your strength and resilience. What helped you get through? Was there something in particular that can help you through a future crisis?
- Find two new people to baby-sit your child. Write down their names and phone numbers.
- Talk to your significant other or partner about how you are feeling.
- Today, make a date with each of your other children to do something special.
- Write down a response you can give to strangers when you don't feel like explaining, but don't want to be rude. Having a response ready will make the situation easier.
- Be prepared. Make a list of questions now to take to your next doctor's appointment, therapy session, meeting with a teacher, etc.
- List the ways you are a good parent to your child.
- List the things you do for your child that he can do for himself. Decide to let him.
- Plan two things you'll do for yourself this week. Write them on the calendar now.
- Find someone to talk to...your partner, friend, counselor, clergy, support group.

Suggestions from *After the Tears*/Robin Simon/Family Network on Disabilities of Florida, Inc.



SPEECH & LANGUAGE SKILLS

Submitted By: Kris Everhart, Speech Language Pathologist

Match the speech-language skill with the
typical age of development.

(answers below)

	0-3 mos	3-6 mos	6-9 mos	9-12 mos
1. Turns toward voices.				
2. Aware of and quiets to familiar voices.				
3. Reaches and looks for toys.				
4. Makes sounds in the back of the throat.				
5. Uses different cries for different reasons.				
6. Vocalizes 4 different consonant-vowel combos (ex: mama, gaga, dada).				
7. Makes sounds with people and when alone.				
8. Participates in simple games (i.e., peek-a-boo).				
9. Waves "bye-bye".				
10. Makes brief eye contact.				
11. Gestures w/vocalizations to protest or request "up".				
12. Gives objects on request.				



Answers:

- | | |
|------------|--------------|
| 1. 3-6 mos | 7. 3-6 mos |
| 2. 0-3 mos | 8. 9-12 mos |
| 3. 6-9 mos | 9. 9-12 mos |
| 4. 0-3 mos | 10. 0-3 mos |
| 5. 3-6 mos | 11. 6-9 mos |
| 6. 6-9 mos | 12. 9-12 mos |

The above answers are only guidelines – children develop at different rates. If you have any questions or concerns about your child's development, please talk with your primary care physician or your Child Development Watch family service coordinator.

MY EARLY INTERVENTION JOURNEY

By: Michelle Lamers



When I became pregnant I knew I was in for some changes in my life. I had no idea of the course my life would take. I would like to share some of my journey with you and explain how I became involved in the Early Intervention system. An ultrasound at nine weeks showed I was carrying two babies. Twins proved to be a great surprise. These babies surprised me again by deciding to be born early. I delivered Brady and Brett, identical twin boys, at 30 weeks. They were small and only 2 pounds each. After many weeks in the special care nursery, they finally grew and were allowed to come home. At the time of their discharge, Child Development Watch was called. I had no idea that a service like this even existed. I went along with all they suggested. Developmental nurses and service coordinators became common fixtures in our lives, as well as frequent visits to the CDW clinic. It was a bit overwhelming for me, but I wanted to do what was best for my babies.

Things seemed to be progressing well, until Brady started to move around and explore. Brett could only stay on the floor where I left him. What was happening with Brett? I was determined to find out. I finally convinced their pediatrician that he needed a specialist. After more appointments and an MRI, he had a diagnosis. My baby had Cerebral Palsy. Once again, I was overwhelmed but determined to do what was best.

We began therapy at Easter Seals. As I reflect back on this time, it just seemed so normal to go to all these doctors and therapy sessions. I was always busy driving and showing up when I was supposed to. When the twins were in preschool, their brother Bryce was born on time and healthy. He fit right into our life. Once the twins were in school and Bryce went to preschool, I found I had a small amount of extra time. I received a survey in the mail. It was a call for parents who currently had a child in Early Intervention or were already finished with the system. It seemed perfect for me, so I responded to the survey. One of the questions was would I be willing to travel to North Carolina as part of a team that would be trained to work for change in how our future teachers and therapists would be taught. It seemed intriguing, so I responded yes. That yes has changed my life! I was chosen to go and since then, I have had the opportunity to meet and work with the most wonderful people in our state. Since my initial training, I have become a Family Support Partner for Child Development Watch. I also serve on several committees as a parent representative. This work has allowed me to share my unique perspective with people who truly value what all of us face as parents of children with special needs.

I wanted to share my journey with you because we need more parents who are willing to say yes and become involved in the great work that we have started. I hope that you will consider joining us in our work to make Delaware a state that values parents and their perspective in Early Intervention. Please see the survey on the back of this page and say **YES!** Thank you.

SURVEY

Dear Parents:

Early Intervention needs your **help**!

If you would like to become an **advocate** for your child and others in our state, then here is your chance!

You can

- Learn to write and tell your family story
- Help train teachers, therapists, nurses, Early Intervention staff
- Work to develop new state programs and improve existing ones

Please contact Michelle Lamers to discuss these opportunities. You can reach her at (302) 378-0170 or through e-mail at LamersMM@aol.com. You can also express your interest by returning this survey to your Child Development Watch Family Service Coordinator!

We need your voice!

Name: _____

Address: _____

E-Mail Address: _____

Phone Number: _____

Area(s) of Interest: _____



